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TESTIMONY OF

**DIANE M. ZUMATTO
AMVETS NATIONAL LEGISLATIVE DIRECTOR**

BEFORE THE

**HOUSE COMMITTEE ON VETERANS' AFFAIRS, SUBCOMMITTEE
ON OVERSIGHT AND INVESTIGATIONS**

U.S. HOUSE OF REPRESENTATIVES

***ONE HUNDRED THIRTEENTH CONGRESS
SECOND SESSION***

CONCERNING

A LEGISLATIVE HEARING ON:

**HR 4261:
GULF WAR HEALTH RESEARCH REFORM ACT OF 2014**

EXECUTIVE SUMMARY

AMVETS supports HR 4261, the Gulf War Health Research Reform Act of 2014, which would:

- establish the RAC as an independent committee within the VA with its own budget;
- require that the majority of the RACs members be appointed by the chairmen and ranking members of the House and Senate Veterans Affairs Committees;
- strengthen the RACs ability to review research and studies as well as publish reports related to Gulf War Illness (GWI);
- expresses the sense of Congress that VA should contract with the Institute of Medicine to conduct several Gulf War studies and reports previously ordered by Congress, which were not conducted or weren't conducted in accordance with Congress' direction;
- require the VA to ensure that research conducted on this disease be referred to as "Gulf War Illness";
- with regard to future research, require that Institute of Medicine (IOM) reports on the health effects of veteran toxic exposures, consider animal as well as human studies, as Congress has previously ordered, to better understand the causes and how best to treat our afflicted veterans

If we ever expect to understand GWI, if we ever expect to develop medically appropriate treatments for it, and if we ever hope to truly improve the quality of life of our Gulf War veterans, then continued research, as well as adequate, on-going funding, is absolutely vital. Our veterans didn't give up while they served overseas; they risked their lives and their health for the good of all American citizens. It's time for this country to hold up its end of the bargain by doing everything possible to take care of the healthcare needs of our Gulf War veterans.

AMVETS believes this legislation can be part of the solution that Gulf War veterans have been waiting 23 years for.

Chairman Coffman, Ranking Member Kirkpatrick and distinguished committee members, while I am pleased to have this opportunity to sit before you today, I am simultaneously disheartened that it is because we're still dealing with administrative issues rather than making progress towards the understanding and treating of the scourge that is Gulf War Illness.

Twenty three years have passed since the end of the Gulf War and sixteen, since Congress first mandated (Public Law 105-368, the Veterans Programs Enhancement Act of 1998) the appointment of a public advisory panel of independent scientists and veterans to advise on federal studies and programs to address the health consequences of the Gulf War. The Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) was originally appointed in 2002 by Secretary of Veterans Affairs Anthony Principi, who directed the committee to, "*provide advice and make recommendations* to the Secretary of the Veteran Affairs on proposed research studies, research plans and research strategies relating to the health consequences of military service in the Southwest Asia theater of operations during the Persian Gulf War."

In the 'Objectives and Scope of Activity' section of the committee's original 2002 charter it is further stipulates that the RAC, ". . .shall review all proposed federal research plans, initiatives, procurements, grant programs, and other activities in support of research projects on Gulf War-associated illnesses and assess the individual projects and the *overall effectiveness of government research* in addressing central questions on the nature, causes and treatments of Gulf War-related illnesses." There can be no doubt that the RAC, in conjunction with the VA, has been charged over the years with important, and in some cases, life or death responsibilities and AMVETS is appreciative of all the work done by both entities.

Research has shown that Gulf War illness is associated with service in the 1991 war; that it affects at least 175,000 veterans; and that it is a physical condition caused by toxic exposures, rather than stress or other psychiatric factors.

Symptoms typically include debilitating fatigue, cognitive and other neurologic symptoms, gastrointestinal problems, skin problems, chronic widespread pain, and persistent headaches or migraines. Gulf War veterans also have elevated rates of ALS, Lou Gehrig's Disease and there is concern that Gulf War Illness could develop into life-threatening neurological disorders as this cohort ages. Unfortunately, at this point in time, there are no effective treatments.

AMVETS' only concerns regarding the subject of this hearing are simply - the health and quality of life of our Gulf War veterans. For more than 20 years now, these men and women have suffered, and continue to suffer, from the often debilitating effects of Gulf War Illness (GWI). How much longer will they be expected to wait to get relief from their decades-long pain and distress?

AMVETS fully supports the concept, purpose and work of the RAC. We believe that their work over the years has been instrumental in helping to:

- shed light on the underlying causes of GWI;
- examine treatment options for those currently afflicted;
- ensure that adequate research funding is requested;
- act as a catalyst, bringing together VA and non-Va researchers;
- consider countermeasures for long-term, low-dose exposures to protect current and future servicemembers; and
- identify additional focus areas for future research.

I would suggest that it is common knowledge that bureaucracies, and VA is among the largest, are not well known for their transparency, creativity or ability to ‘think outside the box’; therefore, it makes good sense to have an independent, non-partisan and transparent body, with its own support staff, nothing to lose and no hidden agendas, composed of medical professionals, research experts, veterans and other stakeholders, so prominently involved in this important work.

Additionally, by openly allowing academic subject matter experts and medical professionals to participate in RAC activities, the best and brightest are able to contribute and act as force multipliers towards resolving the problem of GWI.

AMVETS, as one of the authors of the *Independent Budget*, as a member of the Military Coalition (both of whom take strong positions on the issue of GWI) and one of the preeminent, congressionally-chartered veteran service organizations in the country, is extremely disappointed that the VA often appears to be working at cross-purposes with the RAC and has failed to act on recommendations made by the committee in June 2012 and February 2013.

Among the concerns outlined in the 2013 RAC Annual Report:

- VA did not add questions to its national survey of Gulf War veterans that would enable it to determine the prevalence, progression or correlates of the illness;
- VA did not modify the contract for the Institute of Medicine (IOM) treatment report to conform to Congresses intent;
- VA re-set its budgeted Gulf War research spending in FY 2014 to \$15 million; however, VA has historically not spent the amount budgeted and the amount spent has included significant numbers of studies not actually directed at Gulf War Veterans;
- VA concluded a contract for the development of a case definition with the IOM through a literature review by a committee with little expertise in the illness,

although this is contrary to standard scientific practice and the IOM has never done a case definition of an illness before;

- In May 2013, VA changed the committee's charter to eliminate its authority "to assess the overall effectiveness of government research to central questions on the nature, causes and treatments for the health consequences of military service . . . during the 1990 – 1991 Gulf War" and
- The charter change also calls for the elimination of the provision granting the committee its own staff, as well as, the replacement of half of the committee members this year and the balance in 2015.

I hope that these concerns and others expressed today indicate why AMVETS supports, HR 4261, the Gulf War Health Research Reform Act of 2014. This concludes my testimony and I'll be happy to answer your questions.

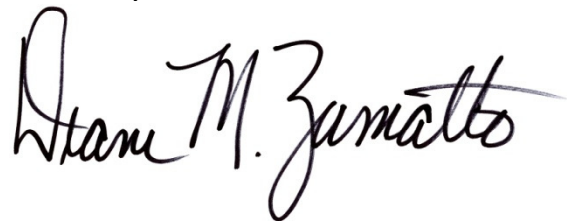
21 March 2014

The Honorable Representative Mike Coffman, Chairman
U.S. House of Representatives
House Committee on Veterans' Affairs
Subcommittee on Oversight and Investigations
335 Cannon House Office Building
Washington, D.C. 20510

Dear Chairman Coffman:

Neither AMVETS nor I have received any federal grants or contracts, during this year or in the last two years, from any agency or program of the federal government.

Sincerely,

A handwritten signature in black ink, reading "Diane M. Zumatto". The signature is written in a cursive, flowing style with a large initial "D" and a long, sweeping underline.

Diane M. Zumatto
AMVETS National Legislative Director

Biographical Sketch

Diane M. Zumatto of Spotsylvania, VA joined AMVETS as their National Legislative Director in August 2011. Ms. Zumatto, a native New Yorker and the daughter of immigrant parents decided to follow in her family's footsteps by joining the military. Ms. Zumatto is a former Women's Army Corps (WAC) member who was stationed in Germany. Zumatto was married to a CW4 aviator in the Washington Army National Guard and is the mother of four adult children. Ms. Zumatto is extremely proud that two of her children have chosen to follow her footsteps into military service.

Ms. Zumatto has more than 20 years of experience working with a variety of non-profits in increasingly more challenging positions, including: the American Museum of Natural History; the National Federation of Independent Business; the Tacoma-Pierce County Board of Realtors; the Washington State Association of Fire Chiefs; Saint Martin's College; the James Monroe Museum; the Friends of the Wilderness Battlefield and the Enlisted Association of the National Guard of the United States. Diane's non-profit experience is extremely well-rounded as she has variously served in both staff and volunteer positions including as a board member and consultant.

After receiving her B.A. in Historic Preservation from the University of Mary Washington in 2005, Diane decided to diversify her experience by spending some time in the 'for-profit' community. Realizing that her creativity, energy and passion were not being effectively challenged, she left the world of corporate America and returned to non-profit organization.

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